Medical Child Abuse – A New Perspective - Pediatric Grand Rounds-4-17-2026-Meeting Recording

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1h 2m 15s

Calderon, Delia started transcription

Calderon, Delia 0:03

OK, we are good to go.

Kissoon, Natalie N 0:07

Good morning, everyone. Welcome to Grand Rounds. I am Natalie Kasun. I'm one of the child abuse pediatricians at the Center for Miracles. Some housekeeping things this morning. The attendance code is in the chat and this presentation has been approved for Ethics CME.

So this morning, it is my great pleasure to introduce my friend and colleague, Dr. Shaylyn Nino. She is an associate clinical professor of pediatrics at the University of California, San Diego. The division chief

at UC San Diego School of Medicine and the Medical Director for the Chadwick Center for Children and Families at Rady Children's Hospital in San Diego. She provides medical evaluations for children who are alleged victims of all forms of child maltreatment. Dr. Nino frequently serves as an expert witness in civil and criminal legal proceedings

related to all aspects of child abuse and neglect. Dr. Nina has conducted research in patterns of disclosure in child sexual abuse, methods of testing for sexually transmitted infections in children, social media facilitated sexual assault, and child abuse in the military. And she has many publications that she's co-authored on these topics.

Additionally, Dr. Nino is a graduate of our fellowship program here. We are so proud. And I am just pleased to call her my friend. Thank you, Charlene.

Dr Shalon Nienow 1:41

Thank you, Dr. Kissoon. Good morning, everybody. Today, we're going to be talking about a complicated form of child maltreatment that we call medical child abuse. Medical child abuse is a form of abuse in which caregivers exaggerate, fabricate, or

reduce symptoms or illness in their child, which causes them to undergo unnecessary and potentially dangerous medical interventions. So basically what this means is that we as the medical system are manipulated into taking part in physical and or emotional abuse of the child. You may have heard this called a bunch of different types of names. It's most frequently referred to as Munch House

Amy Quinn 2:19
Eck.

Dr Shalon Nienow 2:24
syndrome by proxy. You may also hear fictitious disorder by proxy, child abuse in the medical setting, or pediatric condition falsification. It doesn't in particular matter the name that we are calling this form of maltreatment, but we have chosen the term medical child abuse on the child abuse
pediatric side to better designate that the abuse is happening to the child and not to indicate what the underlying psychological issue is with the perpetrator of this type of abuse. Just for some little history around Munchausen in particular,
This is the reason, this individual is the reason for the nomenclature, Munchausen by proxy. The term was coined in 1951 by, well, Munchausen was coined in 1951 by Richard Ascher, who described a pattern of self-abuse in which individuals fabricated their own histories of illness.
He named this after this German cavalry officer, Barran Vuong Munchausen, who was known for his dramatic but very untruthful stories. So he was the inspiration for a series of stories that were published anonymously in 1781 and which were later attributed to him.
In 1977, a pediatrician, Professor Roy Meadows, created the term Munchausen syndrome by proxy, a circumstance in which a child was subject to the fabrication of illness by their parent. This was thought to be motivated by the desire of the parent to gain the attention of medical professionals. And because this terminology focuses primarily on the parental motivation,
vision that is why we have altered this to better indicate the abuse that's happening to the child.
Of course, okay, there we go. Munchausen was first entered into the DSM in 1980. It is now termed factitious disorder imposed on another. Again, in child abuse, we don't use this term specifically as it conveys the mental illness of the perpetrator of

this form of abuse. Here are some of the most recent papers published about medical child abuse, just helping us to understand that this is now how we are discussing this form of maltreatment.
The estimated incidence is about 0.5 to 2.8 cases per 100,000. However, it has a really significant mortality rate of 6 to 9%. The average time from onset of symptoms to diagnosis is 15 to 22 months in the literature, but based on our own anecdotal evidence, it really is more significant and often takes many, many years for people to identify that this type of abuse is happening.
When I talk about medical child abuse, I like to explain that this is a pattern or a spectrum of behavior and abuse to the child. With The most.
the least severe form being vulnerable child syndrome and the most severe form being medical child abuse. And so we as medical professionals have two time periods where we can potentially stop this spectrum and involve the rest of the medical team to reduce the harm that's happening to the child. So on that least severe side of the spectrum, this vulnerable child syndrome. This is where a parent has a preoccupation with minor medical conditions. So basically, it's a form of really extreme parental anxiety. This leads to sleep difficulties, the child missing school, undue restriction on activity.
activities of the child due to the parental fear of illness, and oftentimes the anxiety of the parent can induce and or exacerbate anxiety in the child. If this behavior pattern is left unmitigated, it will frequently involve into medical over utilization and subsequently medical child abuse, and that's when the child becomes physically harmed.
Just to illustrate a case in which this is on the lower severity of the spectrum, this is an 11-year-old child who has all of these medical diagnoses to include anxiety, tic disorder, obstructive sleep apnea, ADHD, and urticaria.
Her health concerns started soon after birth with constipation, which as we all know, is a frequent complaint by new parents that is often really not present. Cough and wheeze, with wheezing being a frequent complaint by new parents that is often not present and merely upper airway congestion, and choking, which is also a frequent complaint by new parents and represents disordered suck-swallow coordination,

LS **Leigh Shapleigh** 7:04
Yeah.

Dr Shalon Nienow 7:26

and not actual choking episodes. At 14 months of age, this child had reported hives after drinking almond milk. However, extensive allergy testing was done and did not find any sort of allergy to almonds. So no dietary restrictions were advised by the allergist at that time.

Mother, however, continued to report almond allergy, which was put into this child's electronic medical record. And by age 3, she additionally proffered that the child had milk and soy allergies as well. Over time, this child picked up multiple additional medical diagnoses, as you can see on this screen.

There are some medical diagnoses that were legitimate and real to include the ones here that are highlighted in this purple color. The other ones here that are designated in red were completely ruled out.

by medical testing. And then Tourette syndrome, pica, and feeding difficulties were never independently witnessed by anyone on the medical team. However, all of these medical diagnoses or these problems were put into the electronic medical record and continued and perpetuated over time, which is one of the issues that we see in medical child abuse where even medical issues that have been objectively ruled out continue to be maintained in that EMR and then follow this child over time. So what do we do about this issue?

Step one is really we need to be able to identify.

concerning cases. So how do we do this? One, educating medical providers regarding red flags is really important on the child abuse or child protection side. So we want to understand when there is an undue concern over these normal childhood behaviors. We also want to recognize when there are frequent medical visits that are potentially not needed.

And we want to be on the alert for parents who have a lack of reassurance when told the child is fine. Most times parents want to be told that their child is well and that nothing is wrong. However, when we see these parents who are on this severe anxiety spectrum and moving into the medical child abuse realm,

there is a pattern in which these parents cannot be reassured or take a long time to be reassured when told that their children are well. So then we want to also identify this over-utilization. And this can be tracked using MyChart use or looking at the number of subspecialists that any given child has. Step 2, when we identify

Leigh Shapleigh 9:59

Good morning.

I was thinking I should come here.

You.

Yeah.

Dr Shalon Nienow 10:19

these concerning cases, we want to provide consistent reassurance. When we can do this effectively, then we can stop this at our vulnerable child syndrome stage and potentially de-escalate the parental anxiety and this child can go on to be well. If we get to this medical over-utilization stage where the child is using the ED too frequently, seeing multiple medical specialists,

we can then attempt to intervene so that we're not reaching the time when the child is being physically and emotionally harmed through the medical system. So that's where we really need to focus our efforts because once we get to that medical child abuse stage where a child has been physically harmed,

by the medical system, it's really difficult to undo the significant number of steps that have happened in getting the child to that stage of abuse. So when we recognize these cases, if we are at that medical overutilization stage, we want to make sure that we communicate effectively as medical team members and subsequently de-escalate.

Well, what if...

It doesn't work. So what if we recognize the case, but we aren't successfully de-escalating? That's when we're moving into the medical child abuse realm. This is a sentinel case that happened here at Rady Children's Hospital in San Diego that really altered the way we think about how we as a medical system are responding to these cases.

So this is an 11-year-old kiddo who came in with TPN dependence. Mom was proffering that any enteral intake caused nausea, and then this moved into nausea symptoms were present even in absence of intake, and subsequently the child had a central line placed and was on TPN.

She continued to have weight loss despite high calorie intake, and mother was consistently asking for second opinions and then not following through with those

second opinions. There was significant opioid dependence for this child, with mom asking for opiate refills despite recent prescription refills.

Leigh Shapleigh 12:23
System.

Dr Shalon Nienow 12:30
Mother made this child DNAR despite no objective evidence of her having a life ending or life limiting diagnosis. She ended up being placed under hospice care, again, without a diagnosis of a life ending or life
threatening diagnosis. So this child comes in at 11 years of age and she's admitted to the PICU for shock. She ended up being admitted for 6 1/2 months. She was found to have hyperammonemia, lactic acidosis, acute kidney injury, and was started on CRRT.
Her thiamine level returned undetectable, and other vitamins were also found to be deficient. All micronutrient levels were normalized after repletion, and there was really no logical explanation outside of the failure to administrate
The.
diagnosed TPN. This actually came to the recognition of the medical team when the pharmacy found TPN and lipids stockpiled and unused at the family home. So Child Protective Services were involved and they removed the patient from mother's custody.
This child ended up being weaned off all narcotics. TPN was discontinued, her broviac was removed, and her G-tube was also removed. She completed intensive inpatient eating disorder program because she truly believed that she did not have the ability to eat, so she had to relearn
how to eat like a normal child. She resumed eating by mouth and subsequently didn't have any sort of symptoms. Overwhelmingly, all of her diagnoses were removed. That being said, it is possible that children who are suffering from medical child abuse do have legitimate medical diagnoses.
So this isn't us removing every single diagnosis that a child has. It's us trying to help to understand what are the legitimate medical diagnoses, which ones don't have any objective evidence, and then being able to remove the ones without that objective evidence.
This child had been involved in our medical system for her entire life and had had

really significant involvement of medical subspecialties. When this diagnosis of medical child abuse was made, it was profoundly difficult for all of the medical subspecialists who had been taking care of her.
We recognized that multiple providers previously had concerns for abuse, but did not report them, nor was this written anywhere in her electronic medical record. So this concern couldn't be conveyed to other medical providers. Another issue that we recognized when we looked at this case in depth was that providers were working in silos.
Nobody was communicating with one another about the treatment of this patient. So overall, this patient was being treated for multiple illnesses that she did not have, including muscular dystrophy, pain syndromes, regional
complex pain syndrome to be specific, and a whole bunch of other medical conditions that she objectively did not end up having later on when we recognized the case. So there was a lot of disagreement and arguments within our medical system about who was responsible for this case getting to the point where it was at. And we decided that this isn't about blame. This is how do we find a better way forward. When we have medical child abuse that's happening in the medical system, this isn't us being bad providers. This isn't us making significant mistakes. This isn't us
And.
causing deliberate harm to a child. But we do need a better way to recognize and respond to this form of abuse so that we are not part of the problem. So we here at Rady Children's came up with this idea to start a committee where we look at these cases and try to identify them sooner.
So we created what's called a Medical Child Welfare Committee. This falls under our quality improvement, quality assurance arm within our hospital so that it is completely confidential. It is a multidisciplinary team that reviews cases of suspected vulnerable child or medical overutilization.
And then it supports medical decision making of the treating providers. What we learned from our index case was that many providers were worried about what was happening and the diagnoses that were being made and how they were responding to this case, but they felt like they didn't have support to say no to the mother.
So our committee really does work very hard to support medical decision making of the treating providers so that they feel supported in saying no to parents. It also allows us to have multidisciplinary team meetings of all treating providers across the

health system and across the San Diego region in general.
making sure that we all have the same information and a consistent treatment plan. And it empowers providers to ensure that standard of care is being met. We have published our system for those of you who are interested. It was published in Pediatrics, and this is the name of it here.
After the publication, we got some social media presence that I found particularly amusing. So I thought I would play this to see how some of the people that we are worried about perpetuating this form of abuse responded.
Hello San Diego. Listen up. If you have a medically complex child, in my opinion, it would be very foolish for you to go to Rady Children's. Here's why I am looking right now at an article written by
four or five child abuse pediatricians. And what is the title? Medical Child Welfare Task Force.
colon, A Multidisciplinary Approach to Identifying Medical Child Abuse. Now, if you have read my book, you know that there is an entire chapter devoted to this and an entire part of the book devoted to medically complex children.
What they have done at Rady Children's is set up a task force.
to take children who are medically complex. So if you are a mom walking into that hospital with a medically complex child, you have a target on your back.
So clearly that isn't what we are doing. I thought I made it because I was on TikTok, which I don't even have. So I was pretty amused by this. That is not what we do. We don't kidnap children. This is not our goal. We're not taking children from their parents. Really, our goal is to identify cases early so that the CPS system doesn't have to be involved

LS **Leigh Shapleigh** 19:57
OK.

DN **Dr Shalon Nienow** 20:16
And we can.
eliminate the physical and emotional harm to the child and prevent us from getting to that medical child abuse stage. That woman in the TikTok is a lawyer. She has authored multiple books. She's a really strong proponent for mothers who are perpetrating medical child abuse. Mothers are the most
common perpetrator of this form of abuse. So her being upset at us is probably not a

bad thing. But just to be clear, what our goal is, is to recognize these cases early, de-escalate, and prevent us from getting to the stage where children are being harmed. This is our algorithm. So we did a really significant
push for education about recognition across the health system and in the San Diego region so that cases can be identified by either Rady staff or their PCPs, and then they can consult with our team. Our team will do a brief chart review and then determine if there is a concern and we need to refer this patient to the committee or if this child needs to be admitted and then an inpatient consultation can be done. The medical record review is relatively extensive in all of these cases, so it is very time consuming, and it's one of the most significant drains on the medical system in general.

LS **Leigh Shapleigh** 21:43
Flat lining.

DN **Dr Shalon Nienow** 21:43
We will.
We will review this with the medical team, and sometimes this can be resolved, or we may need a multidisciplinary conference across all of the subspecialists of the child. We also have created a dot phrase for in basket messaging of all the existing care team providers.

LS **Leigh Shapleigh** 21:45
You.
I supposed.

DN **Dr Shalon Nienow** 22:06
And we also have developed a way to communicate with outside physicians in order to bring them up to speed with our concerns. And really the only goal for us is to help alert providers to our concerns about medical over utilization.
so that people are being very intentional in how they're thinking about the way that this child needs to be treated from the point that the concern is identified and moving forward. We can do multidisciplinary team meetings, which we do on a quarterly basis to review all of the cases that are on our flagged list.
It is led by the co-chairs, which is myself and a hospital medicine physician. Our

paper was actually authored by two hospital medicine physicians, myself and one of our fellows. So it really wasn't four or five child abuse pediatricians. And we also loop in all of the subspecialists involved in the patient care.
Nursing leadership is involved if the child is inpatient because it really helps support the nurses who are dealing with this very difficult family. We have ethics members on our standing committee and we always bring in the ethics team if we have an inpatient where this is of significant concern.
Looping in the primary care provider is...
intentional and it is imperative to this process working since they are kind of like the hub of all of the spokes in the wheel for this child getting additional subspecialty referrals and being able to have that de-escalation process work. Our legal counsel at our facility is very supportive of our process.
and can be looped in if there are significant concerns, especially when provider concerns about saying no and about parent complaints come up. And if necessary, we can also loop in our chief medical officer. When we have concerns that medical child abuse or
medical over utilization is happening, we can put an emergency care plan banner into Epic. It is visible in all contexts to all clinicians. There is an ECP smart form where the provider that identifies the concern can complete and sign each individual specialty section.
Data from prior emergency care plan notes will automatically copy forward. So if there's something that is not related to an active emergency care plan or this emergency care plan specifically, then that should be removed. Really, this serves as an FYI flag.
and creates a silent BPA. So that banner will pop up, and then you can see this area that says, click here to launch report. When you do that, it will bring up the note and the concerns that have been identified. And so this is really helpful for us.
when children make it to some different subspecialty or they're presenting to the hospital through the emergency department for all medical providers to be on the same page, which is really the outcome of the multidisciplinary team meetings that we have when they are convened. So we want to make sure that everybody is on the same page regarding next steps.
We want to be able to de-escalate if that's part of our next step plan. And we also want to make sure that further medical treatment is done if it's medically warranted. So this isn't we stop doing all medical care for kids. That isn't the intention. The

intention is that we're preventing unnecessary and potentially dangerous medical interventions when those are not medically warranted.
So we want to stop being manipulated by caregivers into doing those things that aren't standard of care medicine. If we need to report to law enforcement and CPS, we can. And then we can also provide information to other medical centers or physicians regarding our concerns, especially if there's some doctor shopping happening.
because this falls under a HIPAA provision when there is a concern for child abuse and as continuity of care. We have created a dashboard for every patient that we have concerns about. And you can see here are some of the things that we're looking for in our Epic poll. Epic helped us do this. If you all are interested in creating a similar dashboard,
We will loop in our IT because I have no idea how they accomplish this. But you can see when we have high concerns for kiddos, there is this trend for MyChart logins in the last month to be significant. So obviously, if we're having 322 MyChart logins in a month,
That is a really strong indicator for medical over utilization. We look at the number of specialties. We look at no shows, which are somewhat uncommon in the medical child abuse realm. Unless we have children who are having multiple subspecialty visits happening at the same time.
ED visits, admissions, and then imaging studies are also super helpful. So there is this risk stratification score. This is something specific to Epic, and it really isn't necessarily an appropriate risk score for medical child abuse itself, because there are some things that really don't
fit into the medical child abuse realm, like no shows and same day cancellations, which are somewhat rare, and that would confer extra risk. And so that actually confers a little bit of a lower risk from an MCA standpoint, but it was kind of the best system that we could come up to.
with.
Since we started this intervention in this system within our health system, we've reviewed 80 cases of potential MCA. We currently have 27 that are actively being monitored forward. So what happens is that when we're monitoring them, one of the individuals on our child welfare committee will look through the chart occasionally and kind of update what is happening with
the kiddo. There are 30 children who have had formal child abuse consultations by

our team. Sadly, 12 children had to be removed from their caregiver custody because the medical child abuse was so significant. One of those 12 children ended up aging out of the CPS system and returned to his parents care volitionally.
He is now deceased from starvation because those patterns continued once he moved back in with his perpetrators. 25 children had child protective support reports made. I apologize, it's 530 here. I'm still not awake. And 55 cases were successfully de-escalated. And this is our goal. So this really has
help to reinforce that the system that we have in place in early identification and de-escalation is working. It is really hard once we get a child who has multiple surgical interventions, G-tubes, central lines, and this ingrained sick role to be moved
out of that sick role and into the well role. So this successful de-escalation is what our primary goal is with our committee. Some additional outcomes that we have seen is that we have new partnerships with closely located children's hospitals here in Southern California. We also have
collaboration with numerous programs across the country who are trying to kind of imitate the system that we have. And it's really helped us with the ongoing ability to de-escalate these cases. We did receive some philanthropy money to fund chart reviews. So that's where I can get some of our APPs to help us look through the chart and write up
a chart review because they do take significant time.
This isn't without its problems. Anybody who has seen a medical child abuse case knows that these are very, very difficult. One of the most significant issues that we see in medical child abuse cases is a lack of documentation. So this is one of our primary roles of education for providers is to help them understand that they have to document

PH **pat herndon** 30:29
Thanks, you're welcome.

DN **Dr Shalon Nienow** 30:43
anytime they have concerns, because if it's not documented anywhere in the medical record, and then myself as a child abuse pediatrician comes in and says, hey, medical child abuse is happening, CPS and judges in the family court system really cannot understand that this has occurred because they just look at the chart and they're like, oh, look at all these other doctors did all of these other things. Clearly, you're the

only crazy person.
that has this concern. So documenting when you do have concerns is really, really important. This can be very stressful for medical providers who are like, hey, this person is logging into my chart. They're looking for my note. So how can I do this in a way that's safe for me and also safe for the patient? So what I think is the best way to approach this
is that you have your note that you're doing for the visit, and you also have a separate medical decision-making note. When you put that medical decision-making note into your EMR, you have to make sure that you mark it as sensitive. So in our Epic system, there is this little banner up at the top. There's a triangle with an exclamation point in it.
If we hit that, this pop up will come up that says, why are you blocking this note from the MyChart system? And we have a couple of options to choose here. And in the comments, we can say what those options are. So generally, we're saying that sharing the note could cause harm to the patient or another person. When you Except this reason for blocking, you should make sure that this little padlock up at the top is highlighted. That means that this is a secure note and it cannot be seen externally by the parent through the MyChart system. This doesn't mean that it's not discoverable.
So everything is discoverable pretty much. So when we have these charts that are sensitive, they are discoverable if anything ever goes to court. However, at the point that it's going to court, all of this information is going to be seen by the caregivers anyway. The purpose of this is to make sure that there is clear paper trails of the concerns of the medical team throughout the longitudinal care of the
child. And this is an imperative step to us being able to adequately and appropriately intervene for the child. So you have your regular note that the parent can see, and then you have this sensitive note that the parent cannot get unless there's a subpoena for court later on. In our health information management system, anytime I mark a note sensitive,
Our health information management people will reach out to me if there's a request for medical records and say, can I release your note? And I can either say, yes, you can release my note because I've already talked to the parents or no, don't release it because I'm worried about the safety of the child. And then that note doesn't need to be released. And there's a

standard boilerplate language where sensitive notes haven't been released is told to the parent, but they don't say what those notes contain or who wrote those notes.

pat herndon 33:49
I haven't done much adult stuff lately.

Dr Shalon Nienow 33:50
So another thing to remember about medical child abuse cases, when the child abuse team is looped in, someone has to have a concern for MCA before I ever get looped in. So this is never just me having the concern. However, what we want to make sure that's not happening is it's not just me documenting concern. So what are the barriers to us having
correct identification of these cases. One, these caregivers are very medically savvy. They are often medical professionals or have some sort of contact with the health care system, and they understand how to talk about these issues. They speak in medical jargon. They can present themselves as well researched, which is why people believe them up front.
We also in pediatrics rely very heavily on history provided by caregivers, and we assume that this history is truthful because we have to. However, if it's not making sense, if the child in front of you doesn't look the way the parent is saying they are behaving, then it should be a trigger for us to be
a little bit skeptical about whether this history is truthful. If we have children who are verbal, it's often extraordinarily helpful to separate the child from the caregiver for medical history gathering, if that's possible. Recognition can often take years, and then it's really difficult retrospective.
to look back and be like, oh shoot, I should have caught this a long time ago. But that just makes you human. It doesn't make you a bad physician. So it is a barrier. We know that. So that's why we're working on improving our recognition. These caregivers tend to be very forceful. It initially appears like strong advocacy for their child, but really becomes
quite bullying as the form of maltreatment gets worse. They'll demand procedures, they'll threaten legal action or say they're going to complain about you or turn you into the medical board or do all of these other things. But they really don't have a leg to stand on if you're following standard of care medicine. So that's a really

pat herndon 35:55
I.

Dr Shalon Nienow 35:59
important point for you to remember. These cases are also extraordinarily time consuming and emotionally taxing. So many times we are doing things as providers that we may not normally do because we just want this person to get out of the office or out of the ED or wherever they are.
And so they rely on this emotional tax in order to manipulate caregivers into doing what they want. As children get older, they're going to be co-opted into assuming the sick role, and they 100% believe that they have been sick. The person that they love and that they trust the most in this world has been telling them for years and years that they are sick, and they believe that they are.
So as they get older, they will also start to take part in the fabrication and exaggeration of their own symptoms. And this is part of the psychological abuse that goes along with this form of maltreatment. And so it often takes a really significant effort in therapy and trauma treatment in order to get those kids
back on a path to wellness. The number one treatment and the gold standard treatment for medical child abuse is to remove the caregiver who is
causing these symptoms or encouraging these symptoms in the child from the bedside. So this is where CPS comes in because they can legally remove the child. You may have a policy at your hospital where if active child abuse or if inhibition of appropriate medical care is happening, you can remove them by policy. We have a policy at our institution. If not, Child Protective Services is really generally our best bet for getting removal of a caregiver from the bedside. When caregivers are removed from the bedside, the de-escalation can happen relatively rapidly.
So when the child isn't having the caregiver who's either inducing the illness or encouraging the illness, then that illness and all of the symptoms that are being proffered for that illness tend to dissipate relatively rapidly. And then we can really get down to what is physiologically present versus what is not. Covert video surveillance can be used when there are concerns that aid
parent is tampering with medical
What's the word I'm looking for? So when they're either trying to induce illness by putting feces in a child's central line, for example, or they're tampering with feeding

pumps or doing something of that nature, smothering a child, covert video surveillance can be a good medical diagnostic tool.
emphasize that because it is for medical diagnosis and treatment. I am not an investigator. We are not investigators in the health care system. We are doing this for the sole purpose of medical diagnosis and treatment. You just have to work with your legal entities and within your policy at your hospital if this is something you think
can be helpful to making the diagnosis.
When investigators become involved, they will obtain all medical records from all institutions that this child has ever been at. They will also ask medical professionals about concerns that they may have not documented. So if a case of medical child abuse does occur,
You may be asked, have you ever had concerns? And it's really important from the investigative side to be very honest about what objective concerns you have had for the care of this child or for the parents' behavior in your care of this child. They will also find out from collaterals if those collaterals have ever had concerns. So this is where they're talking to neighbors, friends of the family,
me and other family members about concerns for medical over utilization. When a formal report is done by a child abuse pediatrician, these tend to be extraordinarily extensive. This is a small excerpt from a chart review that I did of a
teen child. It ended up being 36 pages long. So this is what is...
so difficult about these cases because you have to sift through years and years and years of medical documentation to look at what are the imaging studies that prove some objective findings? What are the labs that prove some objective findings? What are the labs and imaging studies that have completely ruled out medical entities?
so that we can kind of keep up with the problem lists in children's electronic medical records and remove the ones that aren't present.
I often get asked like, why are people doing this? What is the motivation? There may be multiple motivations. There may be different motivations. Those motivations can switch over time. There is a significant secondary gain for these caregivers for caring and advocating for this medically complex child. They will get a lot of secondary gain in their mommy groups.
in their blogs online, from social media itself. Oftentimes, you'll see GoFundMes for these children. They're taking part in Make a Wish. They're often on the media. And as the child gets older, they can also have their own social media presence. So

significant secondary gain that goes into this form of child maltreatment.
There also may be financial gain. I've seen caregivers who get free housing, who get monthly stipends, who are getting paid to be the service provider for the child, despite the child not having objective evidence of the thing that they're being cared for. So there may be a really profound financial gain driving this behavior.
And there's also some psychological fulfillment in these cases in being a caregiver and having this codependent relationship with their child. Many, many times in cases that I have been involved in of medical child abuse, we don't really know what the underlying motivation is. We can often guess, but it is really difficult
for these forms of abuse, for there to be adequate rehabilitation of the caregiver so that they can be a safe caregiver moving forward. Adequate rehabilitation requires that the caregiver recognize their underlying motivation
and modify their behavior. And many times the caregivers cannot and will not do this. So we may not ever learn the motivation, but these are some of the possibilities for why any given child that you're seeing may be involved in this form of abuse.
So some take home points. For medical child abuse, you really have to have a high level of suspicion that the information being provided to you is not real. So kind of have a questioning attitude. Look at the objective evidence that is in front of you. If the objective evidence doesn't make sense compared to the symptoms that are being proffered,
then it probably isn't real. We really want to identify risk factors, especially early on, so that overutilization of the health care system, anxiety about those normal childhood behaviors, and be worried about any symptom that cannot be independently verified. So if mom says this kid is vomiting,
all of the time after every feed, but inpatient, there is no objectively verified vomitus. So, oh, well, I cleaned it up, or, oh, they went and vomited in the toilet and I flushed it down the toilet. If we don't have objective evidence, then we really can't prove that that symptom is real. We also want to be alerted to symptoms or disease processes that aren't responding to normal interventions.
So if mom says this child has POTS and all of our normal treatments for POTS aren't working, then probably this child doesn't actually have POTS. And so then we need to rethink that diagnosis. We also want to be alerted to caregivers who refuse to acknowledge when a child is well. If a parent or caregiver is being
is getting upset because you're saying their kid is fine, that is not normal behavior, and that is a red flag for this form of maltreatment. We also want to be concerned

when parents are insisting on invasive procedures that aren't necessary. So this also isn't normal. We don't want kids to undergo surgeries if they don't have to have surgeries. So
watching for this red flag is really important. Doctor shopping, refusal for less invasive forms of treatment, primarily things like physical therapy, occupational therapy, emotional therapy. These types of caregivers are very resistant to those less invasive forms of treatment or will say, oh, well, that doesn't work.
and really insistent on more physically harmful invasive studies. You may see things on mainstream media about medical child abuse. This is a website that our field is really well versed in called Medical Kidnap.
You may see all of these media stories, take care of Maya, for example. But what's really imperative that you all understand is that these stories appear very compelling because they have an agenda. It's A single-sided agenda. The physicians involved in these cases cannot speak about them because they are
bound by HIPAA laws. And so this sexy story of doctors kidnapping children from their parents and holding them against their will and falsely accusing parents is.
kind of how our society, what our society likes. They like the, you know, drama involved with all of these stories, but recognize these stories are very one-sided. If anybody wants to hear a really good, objective review of Take Care of Maya, for example,
This is a great podcast by Andrea Dunlop. It's called Nobody Should Believe Me. You can find it on Apple Podcasts or wherever you listen to your podcasts. Season 3 goes over the Take Care of Maya case and objectively looks at both sides of the story just so that people can understand kind of the nuances and the complexity.
of dealing with these types of cases.
So overall, the point of me coming here to speak to you about these cases and us trying to recognize these cases early is that we as the medical system really need to do no harm. That is our primary goal. And this form of abuse does come with harm at the hands of the medical system. And that's what we're trying to prevent.
We cannot be part of the problem. And in order to not be the problem, we have to recognize it early and not be pushed into doing things that can harm kids. I want to leave you with this poem that was written by one of our children who suffered from medical child abuse. This is that 11 year old child, the index child for how we have changed our process at Rady Children's Hospital.
She does a lot of conferences with us and by herself to kind of talk to medical

providers about her experience. And one of the things that she likes to point out is that no one ever asked her how she was feeling or
what was going on with her. They only ever talked about her to her mother. And so her experience, I think, is...
really poignant. And she's the reason that we do what we do in the child abuse world, because saving her really was the best thing the medical system could have done. And so her words are much more powerful than my words, and I will leave you with those.
I'm happy to answer any questions about this form of child maltreatment or about the way that we handle these cases at Rady Children's, if anybody has any. Thank you so much for your time this morning.

Kissoon, Natalie N 48:47
Thank you, Dr. Nino. That was such a great comprehensive talk. Does anybody have any questions? Let me see if I can see. Dr. Williams, I see your hand is raised.

Williams, Janet F (Dr.) 49:00
Um...
Yes, I just wanted to make a couple comments. I thought that was really fantastic. And I think there's some traps now that are so pertinent for physicians to not be complicit with this, basically.
And one is just, these aren't going away. I don't think they're bad. I mean, I'm just saying the state of our...
culture right now is this huge access to information and social media and the internet. And the fact that what I have seen over the years is people really don't like normal.
They're really into drama. And so the more dramatic you can say, you know, if you had a normal pregnancy or a normal child, that's not interesting. You have to talk about all the things that went wrong. And I think we have to emphasize over and over when we see patients,
your child is normal. You've done a good job. This is wonderful. To just calm them down. So that's one point. The other point is even when medical records were paper, it was problematic to, because of
the pressures and the time and how fast you have to do things and blah, blah, blah, which has gotten remarkably worse.

The problem was perpetuating myths. And people would come in with a suspected something, let's say, in the ED, and that would be perpetuated. And you'd say, no, no, that was maybe a working diagnosis, but it was never proven.
It's even worse now. And just yesterday, I was saying, do not put that in their record. It's never proven it was a suspicion they came in labeling their child. And you're just perpetuating this myth because we're under so much pressure to operate quickly. we probably won't read through, or sometimes there's the copy and paste, just forward, you know, just forward these things. But really thinking about what is actually important for the health of this child, for the picture you're painting, and for their future. And you can put
in your notes suspect this or why you don't. But I think we have to be extremely careful about not perpetuating falsehoods.

PRIMROSE MEIER 51:50
Okay.

Dr Shalon Nienow 51:54
One 100%, you could give my talk. Thank you. And it's so true. And it's sometimes exhausting for the consistent reassurance, but really that's the best way to kind of de-escalate these cases. And if you know something has been ruled out, remove it from the problem list because the perpetuation is really

Williams, Janet F (Dr.) 51:54
Thank you.
Yeah.

Dr Shalon Nienow 52:14
profound. So thank you for those comments. Super true.

Williams, Janet F (Dr.) 52:17
Thank you. Yeah, thank you. It was a wonderful talk. Thank you.

Dr Shalon Nienow 52:21
And another.

Kissoon, Natalie N 52:21

I know I was like...

DN **Dr Shalon Nienow** 52:23

Another concern that I think is important is this whole notion that how parents rate us through these like...

Kissoon, Natalie N 52:24

Go ahead, Sher. Go ahead.

DN **Dr Shalon Nienow** 52:35

patient satisfaction surveys drives bonus money or part of your salary, that really works against us as physicians in being able to tell families no, because these parents are not going to be happy unless you do what they want, and that can affect your livelihood.

And I think the way we have the medical system set up can really work against children when this form of child abuse is happening. So.

Williams, Janet F (Dr.) 53:04

And we tend to do that as we're now we're asking everybody if they will accept a vaccine. Okay, you do have to approach that in an appropriate way, but it's kind of like they are driving all the medical care and we're just accepting their advice.

And it's a balance. It's a very delicate balance of them trusting your expertise and you trusting your informing them correctly and allowing them, you know, their part of it and their decision making, but not handing it over to them.

Totally.

DN **Dr Shalon Nienow** 53:47

Absolutely.

Kissoon, Natalie N 53:50

Dr. Lynch.

Lynch, Jane L 53:55

What a great talk. So endocrine always attracts these families. And I think so many good points were made for people to learn about. We live in a city with

Dr Shalon Nienow 54:13
Oh.


Kissoon, Natalie N 54:14
Oh no, I think Dr. Lynch got disconnected. Hopefully she'll come back on.

Dr Shalon Nienow 54:20
Yes. There is a question in the chat, Dr. Wood. Is there a decision making process or algorithm about when or how to disclose to the parent that medical child abuse is under consideration? That really depends on if you think that's going to be safe for the child.


Kissoon, Natalie N 54:25
Okay.
Yeah.
Yeah.

Dr Shalon Nienow 54:39
HIPAA allows that you do not have to disclose your medical diagnosis or any sort of medical information to a caregiver if it's going to cause imminent risk to the child. So if the child tells you, my parent is doing this, you don't have to disclose that to a parent. I tend to be very, very honest when I start to get involved, and I'm usually involved way down


Kissoon, Natalie N 54:39
Yeah.
A
Yeah.
Yeah.

Dr Shalon Nienow 55:04
stream with parents so that they know that it's coming. If you're in the information

gathering stage, it may not be the best time. So I don't know if there is a specific algorithm. It's, is it safe for you to disclose this to the parent? Is it safe for the child for you to?

Kissoon, Natalie N 55:14
Yeah.

Dr Shalon Nienow 55:24
disclose it to the parent. And have I experienced difficulties with staff or specialty physicians disclosing prematurely resulting in increased weariness? I haven't run into that specifically because most people are really afraid to say these things to parents. So that is more my experience.

Kissoon, Natalie N 55:24
Okay.
Probably.

Lynch, Jane L 55:35
We have to run into that specifically, because most people are afraid to say these things.
Not so.
Is more about doing?

Dr Shalon Nienow 55:45
But that is a potential barrier.

Lynch, Jane L 55:46
I think.

Dr Shalon Nienow 55:49
Really good questions. Is Doctor Lynch back at all?

Kissoon, Natalie N 55:55
I didn't, I don't see her. I'll keep checking. Dr. Rayas. Rayas.

Rayas, Maria S 55:58
Hi, actually, I raised my hand and Dr. Lynch is with me, so she's going to ask her question.

Lynch, Jane L 55:59
Hi.
Oscar.

Dr Shalon Nienow 56:01
Perfect.

Kissoon, Natalie N 56:02
Okay.

Lynch, Jane L 56:04
No.

Rayas, Maria S 56:05
Actually, I think I'm back on the mic. There will probably...

Lynch, Jane L 56:05
Yeah.
Yeah, go back to.
Ah.
Are there some helpful comments which are really suspicious and you have talked to the PCP? What do you find de-escalates it in terms of a conversation with a parent?

Dr Shalon Nienow 56:31
I would say in true medical child abuse, these parents don't de-escalate personally well when you're saying your child is okay. What is the most important thing for you to do is to just stand your ground. You know what is medically necessary and what isn't.

Kissoon, Natalie N 56:33

And.

Lynch, Jane L 56:34

She.

Stop.

What is?

Book.

Okay.

Dr Shalon Nienow 56:51

and be supported by the rest of your peers and your medical colleagues in being able to say no when you need to say no. These parents are not going to be happy when you tell them that their child is well. They just are not. And sometimes we cannot make people happy, but really being very

Lynch, Jane L 57:00

S.

Three.

Dr Shalon Nienow 57:11

concise and clear with this is not going to happen. It's not going to happen today. It's not going to happen tomorrow. And moving them out of the office is the best way to approach it because you're just never going to make people who are perpetuating this form of maltreatment okay.

Lynch, Jane L 57:24

Other.

Dr Shalon Nienow 57:30

When we're on the vulnerable child end of the spectrum, it's really just consistent messaging. But once we're at this point where parents are causing harm to their children by insisting on medical care, they're just going to be unhappy. And you have to sit in that discomfort, which is not the answer anybody wants to hear.

pat herndon 57:37
Some.
Bob.
No.

Dr Shalon Nienow 57:49
Yeah.

Lynch, Jane L 57:51
Yeah. No, no. And one of, luckily we have a really cohesive team, so we meet every Friday. So like as these patients always, doctors shop even within the division and then they go outside the division, at least we could have one
united go to and we tend to not allow the patients to switch for the most part to another physician within the group unless there's major conflict.

Dr Shalon Nienow 58:22
That is like the perfect response. It's the united front that is really the only way to kind of reduce some of this from happening. So I'm really hopeful. You're so welcome. It's really great that you guys are handling that way, and I'm really hopeful for your group. That's perfect.

Lynch, Jane L 58:33
Thank you so much.

Kissoon, Natalie N 58:46
Any other questions?

Dr Shalon Nienow 58:50
There's a question in the chat since the parents doctor shop and it's such a big city. Yeah, welcome to my world. What is our responsibility to report about the child if we don't see them again? So it depends. Do you have reasonable suspicion that abuse or neglect is happening? Then it's your

Kissoon, Natalie N 58:51
Chat. And yes, I see it.

Dr Shalon Nienow 59:10
duty to report that by law. I have found that if you just have a concern, directly relaying that concern to the next medical provider is really helpful because if they know up front what you know, then they are less likely to be sucked into the vortex of
these families, and then you can get a united front across multiple health systems, which we do here in town. And that's a HIPAA provision for continuity of care, and because there is a concern for child abuse. So being in communication with your colleagues, especially if you know colleagues out in the medical
community is really helpful. And I will often forward my notes to those medical colleagues if I don't know them, somebody I know knows them. One of my co-chair of our committee, who's a hospital medicine physician, basically knows everybody. And she can reach out to those colleagues and give them a heads up.
Our neurosurgeons have been doing great with us, actually, and they will reach out to their colleagues around Southern California to give them a heads up. And then it can kind of help de-escalate the process. If you're not to the point where somebody is harming children, then it may not rise to the level of a report. But if you think abuse is happening, you just...

pat herndon 1:00:25
Okay.

Dr Shalon Nienow 1:00:29
Have to report it.
I hope that answered your question appropriately.

Kissoon, Natalie N 1:00:34
Yes, no, and I agree, and I hope one of the things you guys are hearing as a way that we in medicine can help prevent this kind of abuse is communication. So open communication amongst each other within our specialties, but also within other disciplines so that

everyone who's taking care of that child is on the same page and is hearing the same information all the time. That is the only way that we can prevent this from prevent this kind of child abuse is really open communication.

Dr Shalon Nienow 1:01:10
And really, if you have one of these cases, these are hard. They're emotionally taxing and they can be devastating when you look back. And it is just natural for us to have this kind of reaction. So reach out to your colleagues at the Center for Miracles. They are there to help support.
support you in your medical decision making. Nobody likes child abuse pediatricians, not going to lie. So we're kind of used to this sort of response, and they can be a really good resource for you if you just need to kind of debrief some of these cases with somebody, and if you need support.
So.

Kissoon, Natalie N 1:01:50
Absolutely. Echoing that, you guys have our on-call number and emails. Please do not hesitate to reach out to us. We're a little bit over time. Thank you so much, Dr. Nino, for being here. I really appreciate it. This is awesome. And it was good to see your face this morning. Take care.

Dr Shalon Nienow 1:02:02
Thanks, Naveen.
Thanks, you too.

Kissoon, Natalie N 1:02:10
Right.

Dr Shalon Nienow 1:02:11
Bye.

Calderon, Delia stopped transcription